Community fundraising toolkit

chordoma.org
(919) 809-6779
PO Box 2127 | Durham, NC 27702
So, you want to hold a community fundraiser?

Thank you for your interest in raising funds to support the Chordoma Foundation! As a patient-driven organization, our success depends on the initiative of supporters like you.

Every dollar you raise helps the Chordoma Foundation achieve our mission of improving the lives of those affected by chordoma and leading the search for a cure. We are grateful for your desire to help and look forward to working with you.

Whether you’ve hosted community events in the past or are new to fundraising, this Community Fundraising Toolkit is designed to help you plan and execute a successful event on behalf of the Chordoma Foundation.

We want to help you make your community fundraiser as easy and impactful as possible, and look forward to supporting your efforts.

Thank you for helping us improve lives and accelerate cures for everyone affected by chordoma. We couldn’t do it with you!

All the best,

The Chordoma Foundation Team

The Chordoma Foundation has the privilege of being recognized by the Internal Revenue Service (IRS) as a tax-exempt charitable organization. This tax-exempt status is crucial to our ability to carry out our mission. In order to preserve this status, it is essential that you comply with the IRS regulations described in the Fundraising Policies section of our website.
About the Chordoma Foundation

The Chordoma Foundation is a nonprofit organization that serves the needs of the worldwide chordoma community, and partners with healthcare providers, scientists, and companies to improve the lives of those affected by chordoma and lead the search for a cure.

If you or someone you care about has been diagnosed with chordoma, you are not alone. The Chordoma Foundation and a supportive community of peers are here to help you through your journey with this disease.

Our vision is a future in which everyone affected by chordoma is able to overcome the disease and maintain their quality of life. Since 2007, we have served thousands of chordoma patients across the world while dramatically accelerating the search for better treatments.

The Chordoma Foundation would like to thank the following organizations for generously contributing materials to this community fundraising toolkit:

- The Friedreich’s Ataxia Research Alliance (FARA)
- Parent Project Muscular Dystrophy (PPMD)
- Pencils of Promise (PoP)
Getting started

Get inspired

Turn your passion into a community fundraiser! If the idea of fundraising is overwhelming to you — don’t let it be. There are so many creative ways to put your interest and passions to work on behalf of the chordoma community and we’ll be here to help you make it easy and fun. Here are several different types of community fundraisers that have been held to benefit the Foundation:

- Bowl-a-thon and Swing Fore a Cure golf tournament
  Jeff Schilling
- Half marathons
  Steve Mandel
- Surprise birthday party
  Michelle Kalenov
- EP release
  Ryan Van Slooten
- One in a Million Dinner Benefit
  Noreen and Mick Potempa
- Pub crawls and Dodgeball tournaments
  Colleen Riccomini

You can do something similar or something completely new. We will help you find the fundraiser that works best for you!

Schedule a call

If you are interested in fundraising, we want to hear from you, and will work with you to:

- Generate ideas for your event
- Answer questions
- Connect you with someone who has organized an event before
- Kick-start your planning process

We would like to schedule a call with you and then after our call we will send you an email summarizing next steps.

Send in your community fundraising event agreement

Once you have decided on an event, spoken with our development team, and are ready to start planning your community fundraiser, please complete and submit our Community Fundraising Event Agreement (see page 12). Once we receive this agreement we will work with you to set a fundraising goal, create an actionable timeline, provide you with Foundation materials, and help publicize your event.
Planning your event

Set a goal

Setting a fundraising goal for your event is important and requires thoughtful planning. Here are examples of the types of impact that various fundraising levels can provide the Chordoma Foundation. Once you’ve established what type of event you’re going to hold, we will work with you to determine an appropriate fundraising goal.

<table>
<thead>
<tr>
<th>Amount</th>
<th>Impact</th>
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<tbody>
<tr>
<td>$200</td>
<td>Provides one chordoma patient or family with personalized support from our Patient Navigators to help them overcome barriers to getting best possible care.</td>
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<tr>
<td>$1,000</td>
<td>Sequences the genome of a chordoma tumor to uncover the genetic alterations that drive the disease.</td>
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<tr>
<td>$5,000</td>
<td>Supports cell line distribution to 20 labs across the world, enabling research that would otherwise not be possible.</td>
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<tr>
<td>$10,000</td>
<td>Helps trained Peer Guide mentors provide emotional support to patients and their family members for one year.</td>
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<tr>
<td>$15,000</td>
<td>Creates a series of educational materials for patients in six languages to help inform chordoma patients around the world about best practices in care and treatment.</td>
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<tr>
<td>$30,000</td>
<td>Tests one drug in the Drug Screening Program in multiple models to discover new therapeutic options for treating chordoma.</td>
</tr>
<tr>
<td>$60,000</td>
<td>Makes an International Chordoma Community Conference possible. These bi-annual gatherings give chordoma community members from around the world a chance to connect with each other and learn about the latest advancements in research and treatment from top providers, investigators, and community leaders.</td>
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Creating a timeline

We will work with you to create a timeline of activities leading up to your event based on when and where it will be held, how many attendees you expect, and the steps that need to happen between now and then. We suggest giving yourself at least 3-6 months to plan, but you may need as longer depending on the event. Steps may include, but are not limited to:

- Reserving a location
- Obtaining necessary licenses, permits, and insurance
- Recruiting event sponsors
- Enlisting the help of volunteers
- Building a guest list
- Creating an invitation
- RSVP follow-up
- Planning an event agenda

Publicizing your event

We will share tools that make it easy for you to publicize your event. When you organize a community fundraising event, you have a unique opportunity to garner media attention. The effective use of earned media can not only raise awareness about chordoma within your community but also extend the reach of your message, enabling you to raise more funds for research and patient services. We have media relations tools and templates available for free on our website.

Also, never underestimate the power of your personal and social networks to reach and engage new audiences. Facebook, Twitter, friends, and colleagues can all help you broaden your reach with personalized messages that connect and appeal to different groups of potential participants, allowing you to reach the broadest audience possible.

Tip:
Make a Facebook event to promote your community fundraiser

We can help spread the word about your event by including information about it in our social media posts, e-newsletter, and online community. And we can also work with you to create geo-targeted email blasts that reach constituents in your area.

Make posters to hang in your local community, ask friends to help put them up to spread the word

We can send geo-targeted email blasts on your behalf
Gathering materials

We will provide educational materials from the Foundation for your event to help inform your participants about chordoma and what we’re doing to attack it. We can also provide you with Foundation-branded swag to give away at your event. Here is a list of the materials that can be made available to you.

- About Us booklets
- Annual reports
- Banners
- Perseverance bracelets
- Pens
- Sticky notes

Helpful resources

We provide the tools you need to make your event successful, including event waivers, fundraising policies, and media relations templates. Please click on the links below.

- Community fundraising event agreement (see page 12)
- CF Fundraising policies
- Media relations templates
- Sample letter writing campaign

Tip:
Set up a personal fundraising page at chordoma.org/champion to share your story and encourage others to support your event.

Additionally, we can share third-party tools that help simplify the management of your event. A few examples include:

- Ticketing tools, such as Eventbrite
- Onsite payment tools, such as Square
- Promotional item design tools, such as Custom Ink

We are constantly looking for new tools to help make holding a fundraiser as easy as possible and would welcome any additional advice and tips from you!
Collecting donations

To comply with IRS regulations, event organizers have three options for accepting donations. Before selecting the option that’s right for your event, please carefully consider the implications of each option for you and your donors.

Option 1
Each participant makes two payments

How do donations work?
Each event participant pays a registration fee (e.g., meal tickets, golf fees) directly to the event organizer to cover expenses, AND makes a second payment via check or donates online at chordoma.org/donate or through your Champion page to the Chordoma Foundation as a tax-deductible donation.

Please have donors put the name of your event in the memo line of their checks or in a comment on the online form, so that we know these payments are linked to your event.

Does the donor receive a tax receipt?
Yes. Event participants receive a gift acknowledgment letter and tax receipt from the Chordoma Foundation for their full donation.

How does the event organizer pay for the event?
Event organizer pays for event expenses with registration fees that they have collected from participants.

Funds raised through community events go to the Foundation’s annual fund, which is used to support all aspects of the Foundation’s work. Please speak with the development team if you have a particular funding interest.

Option 2
Each participant makes one payment

How do donations work?
Each event participant writes a single check payable to the Chordoma Foundation or donates online at chordoma.org/donate or through your Champion page. The event organizer records the value of any goods and/or services received by each participant, and sends this information, along with all collected checks, to the Chordoma Foundation.

Please have donors put the name of your event in the memo line of their checks or in a comment on the online form, so that we know these payments are linked to your event.

Does the donor receive a tax receipt?
Yes. Each participant receives a tax receipt from the Chordoma Foundation only for the tax-deductible portion of their payment, which is the amount of the payment above and beyond the value of any goods or services received in exchange for the donation (e.g., a gala participant writes a check for $100 to the Chordoma Foundation and the value of the dinner is $40; the donor receives a letter acknowledging their $60 tax deductible contribution).

How does the event organizer pay for the event?
Event organizer pays for all expenses out-of-pocket or through sponsorships and in-kind donations.
**Option 3**
The event organizer takes payment and makes a lump donation

**How do donations work?**
Event participants make a cash, check, or credit card payment directly to the event organizer.

**Does the donor receive a tax receipt?**
No. Event participants do not receive a tax receipt from the Chordoma Foundation.

**How does the event organizer pay for the event?**
Event organizer pays for event expenses with event revenue and sends net proceeds (revenue minus expenses) to the Chordoma Foundation.

*If you choose Option 3, it may be helpful for you to set up a separate bank account, or a subaccount within your personal account, in order to keep money that you raise segregated from your personal funds. Please send one check with net proceeds from this account, along with a detailed report of expenses, to the Chordoma Foundation.*

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**What to do with cash donations**

If you receive cash donations, please go to your local bank and get a bank check (issued to the Chordoma Foundation) for the total cash amount and mail the check to the Chordoma Foundation.

*Please refer to our fundraising policies in order to ensure that all funds are handled in compliance with the IRS and Chordoma Foundation policies.*

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**Please note**

In order for donors to receive a tax receipt from the Chordoma Foundation they must make a payment by check or credit card directly to the Chordoma Foundation. The Chordoma Foundation cannot issue a tax receipt for payments made to the event organizer or any other organization. That means that if you decide to accept payments directly from event participants (Option 3) they will not receive a tax receipt from the Chordoma Foundation. This must be clearly communicated to event participants.

**All bills and expenses are the responsibility of the event organizer.** The Chordoma Foundation cannot, under any circumstances, reimburse event organizers for any expenses.

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Jeff Schilling, chordoma survivor, at an annual bowling benefit he organizes
Finishing strong

Submit your donations

Within 15 days after your event, please:

Send all checks via certified US Postal mail (with tracking) to:

The Chordoma Foundation
P.O. Box 2127
Durham, NC 27702

Email the following to development@chordoma.org:

1. Contact information of event attendees, donors, and sponsors, including any individual or corporations who made in-kind (e.g., non-cash) contributions.
   • If desired, event attendees may receive future communications from the Chordoma Foundation, including event updates, e-newsletters, and solicitations.
2. The type and amount of all donations or sponsorships, whether cash or in-kind.
3. A description and estimated fair market value of any goods and/or services received by each donor.

Share your success and inspire others

We want to hear from you! Let us know how your event went — what went well, what you learned, and anything notable that happened.

Share pictures
We’d love to showcase your successful community fundraiser through our e-newsletter, social media, website, and beyond. Your event could inspire others to fundraise for the Foundation.

Share your event materials
We’d love to see your event materials and be able to share them with others as examples to help future fundraisers.

Tip:
Set up a follow up call with the CF team after your event to talk about what you learned
Send thank you notes

We encourage you to send a personal thank you note to all donors, event participants, sponsors, and volunteers. Expressing your sincere appreciation not only makes participants feel valued, it may also encourage them to support you again at a future event.

We will send a tax receipt to all donors who make payments directly to the Chordoma Foundation. Donors should receive their tax receipt within two weeks of the date that the Chordoma Foundation receives the donation.

In the event that contributions are not tax-deductible, the Chordoma Foundation welcomes the opportunity to thank your participants for attending your event, and we encourage you to send us a list of participants and their contact information so that we may do so.

Before you go

Thank you for considering organizing a community fundraiser to support the Chordoma Foundation! Planning and hosting a community fundraiser is very personally gratifying, and has a meaningful impact on the lives of those dealing with chordoma. While we know it may seem daunting, we’re here to help you every step of the way.

Thank you for being part of a growing community of funders and supporters who are working together to create a brighter future for everyone affected by chordoma!

Questions? Want to talk about a fundraising idea? Please reach out to development@chordoma.org or (919) 809-6779.
Community Fundraising Event Agreement

This Agreement is entered into between the Chordoma Foundation (“Foundation”) and the event organizer __________________________ (“Organizer”).

Organizer plans to conduct a fundraising event for the purpose of generating money to support the mission and work of the Foundation. The Foundation gratefully acknowledges Organizer’s efforts and agrees to use the donation in its charitable work.

Organizer agrees that it has read and will comply with the Chordoma Foundation’s policies related to community fundraising, incorporated herein by reference. Organizer acknowledges that it is not an agent of the Foundation and the Foundation has played no part in the organization or execution of its fundraising event and has no control over it. Consequently, Organizer agrees that it will fully indemnify, defend and hold harmless the Foundation, its directors, and employees from any and all claims that may arise out of or relate to such event, regardless of who might make such a claim.

__________________________________________
Event organizer (Printed name)

__________________________________________
Event organizer’s signature

__________________________________________
Date
About the Event

Name of the event: 

Date and time of the event: 

Location of the event: 

Description of the event: 

Link to a webpage where people can sign up or get more information: 

About the Host

Phone number: 

Email address: 

Personal connection to chordoma: 